The Benefits and Challenges of Involving Adolescents in Medical Education: A Qualitative Study

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ABSTRACT

OBJECTIVE: To explore the potential benefits and challenges of involving adolescents in the education of medical students and residents from the perspectives of adolescents who are hospitalized with chronic health conditions.

METHODS: We conducted qualitative interviews with adolescents at a Canadian pediatric hospital. Eligible participants were those between 13 and 18 years of age who had chronic health conditions lasting more than 3 months and were feeling well enough to participate in an interview. We used conventional content analysis to analyze the data.

RESULTS: Sixteen adolescents participated in the study. In terms of benefits, the participants described how involving adolescents in the education of medical students and residents would improve patient–physician interactions, increase patients' confidence and self-worth, encourage patients to self-reflect and gain knowledge about their health conditions and themselves, and enable patients to socialize with other patients. When asked about the challenges, the participants discussed how it might be difficult to include diverse patient perspectives, manage adolescents' negativity, and ensure that learners are nonjudgmental toward adolescents and take them seriously.

CONCLUSIONS: Although many of the reported benefits and challenges correspond with those featured in the literature on adult patient involvement in medical education, our findings underscore the distinctive benefits and challenges that medical educators may experience in designing and implementing educational initiatives that involve adolescents. Future design and implementation of educational initiatives should further explore the benefits and challenges of such adolescent involvement, because we know that adolescents can be valuable contributors to medical education.

KEYWORDS: adolescent health; medical education; qualitative research

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WHAT'S NEW

This study was the first to explore adolescents' perspectives on the potential benefits and challenges of involving them in the education of medical students and residents. Findings are useful to medical educators considering the involvement of adolescents in educational initiatives.

STRATEGIES HAVE BEEN developed for involving patients in medical education. A review found that patients have given presentations and feedback on examination and communication skills.[1] Educators have also implemented programs where learners meet patient mentors to learn about their illness experiences.[2,3] Research has shown that adult patients want to teach learners about their conditions and that they gain self-worth, confidence, and a greater understanding of their health conditions.[4,5] Learners have commented that these opportunities improved their sensitivity to patients and families, communication skills, and confidence.[2,6] Nevertheless, research has shown that adult patient involvement can also be challenging, as patients feel anxious[6] and vulnerable.[1,3] It also raises challenges with regard to confidentiality, tokenism, and the recruitment of heterogeneous patients.[6–8]

Research has been conducted on adult patient involvement in medical education, but research on adolescent patient involvement, including patients with chronic health conditions, is limited. This gap is disappointing, because 14.8% to 18.0% of adolescents have chronic health conditions that require frequent hospitalizations and interactions with learners.[9] These adolescents can offer unique perspectives to medical education. In a study, adolescents with chronic health conditions said they want to contribute

to medical education. When asked about involvement strategies, adolescents suggested preparing and delivering presentations, videos, handouts, and books on their health experiences and coping strategies; they also proposed mentoring learners on developing rapport with adolescents.[10] However, before operationalizing these suggestions, it is important to investigate the associated potential benefits and challenges. The objective of this study was to explore the potential benefits and challenges of involving adolescents in the education of medical students and residents from the perspectives of adolescents who are hospitalized with chronic health conditions. We focused on adolescents who are hospitalized (rather than those in outpatient settings), because medical students and residents are essential members of their inpatient care teams. These adolescents have frequent interactions with medical students and residents and thus can reflect on these interactions when sharing their perspectives.

The conceptual framework by Lauckner et al.,[3] which focuses on potential benefits and challenges of adult patient involvement in the education of healthcare professionals, informed this study. Although they developed the framework with adult patients experienced in educating healthcare professionals, their work highlights relevant potential benefits and challenges, in addition to describing social and therapeutic benefits for patients, categorized as "personal learning," and benefits to learners and the healthcare system, classified as "making valued contributions."[3] With regard to potential challenges, the framework notes patient vulnerability when sharing their experiences and information, categorized as "potential vulnerability."[3]

Exploring adolescents' perspectives on these and other potential benefits and challenges expands existing knowledge on the comparability between adolescent and adult patients' perspectives on this topic. Because adolescence is a time of physiological and psychological change,[11] adolescents' perspectives may differ from those of adults. This research also responds to calls for educational partnerships with patients.[6,7]

METHODS

APPROACH AND PARADIGM

We used a basic interpretive qualitative approach[12] within a constructivist paradigm. This approach provided a descriptive account from adolescents' perspectives; however, we acknowledge that interpretations are mediated through us as medical education researchers with patient engagement interests.

PARTICIPANTS AND SETTING

Our center's research ethics board approved the study. We used purposeful criterion-based sampling,[13] and participants were from 3 general inpatient units of a Canadian urban, tertiary-care pediatric academic center. Eligible participants were between 13 and 18 years of age with chronic health conditions lasting more than 3 months who were feeling well enough to participate in a 60-minute interview in English. Previous involvement in medical education was not a requirement for participation. To gain insight from adolescents of varying ages and from those with a range of chronic health conditions and experiences, we recruited adolescents from 3 different general inpatient units, each of which provides care for patients with specific diagnoses or conditions. Three medical teams cover these inpatient units. Each team includes 3 to 4 medical students, 2 to 3 junior residents, and 1 to 2 senior residents.

INSTRUMENT DEVELOPMENT

We used a 4-item questionnaire to collect participant demographics. Two adolescents with chronic health conditions assisted in the development of a 5-question interview guide. The first 2 questions elicited interviewees' perspectives on potential involvement in medical education, and the next 2 questions encouraged interviewees to discuss the potential benefits and challenges of involvement. We used the potential benefits and challenges included in the above-mentioned conceptual framework[3] to inform prompts for these 2 questions, which also included prompts with examples of adolescent involvement in medical education. The 2 adolescents developed these examples based on findings from previous research.[10] Our intent was not to focus exclusively on the benefits and challenges of these examples but to use them for stimulating discussion. The final interview question asked interviewees for any additional comments. We piloted the interview guide with 6 adolescents from a hospital-based youth committee and sought feedback from 2 adolescent-focused clinicians.

DATA COLLECTION

From July to September 2016, a research assistant (RA) monitored the electronic admission system to identify eligible adolescents. When the RA identified a potential participant, she notified a healthcare professional on the adolescent's care team. The professional confirmed eligibility and asked the adolescent if he or she would be interested in hearing more about the study. If the adolescent was interested, the RA explained the study to him or her and provided an information letter. If an adolescent was interested in participating, the RA obtained consent and scheduled an interview. During the interviews, the RA used in vivo member checking to verify her understanding of the participants' descriptions. All interviews took place privately and were audio-recorded and transcribed verbatim.

DATA ANALYSIS

The analysis goal was to identify concepts present in more than 1 interview; therefore we triangulated the findings across interviews. We used conventional content analysis to analyze the data because there was limited topical information, and we wanted to derive our coding scheme inductively.[14] First, we independently read the transcripts, highlighting text that illustrated potential benefits or challenges, and created margin notes. We then independently reviewed our highlighted text and notes to identify preliminary codes and create a coding scheme.

We met to review and merge our coding schemes, resolving any disagreements through discussion, and then developed 1 refined coding scheme. We also met with 2 colleagues versed in qualitative methodology and the topic to discuss our preliminary analyses and revised coding scheme. Using this refined scheme, we individually recoded the transcripts and added additional codes as needed. We then reconvened to compare our analyses, again resolving any discrepancies through discussion, and engaged in peer debriefing to select suitable wording for the findings. Finally, we identified exemplar quotations for each coding category.[14] Throughout, we kept memos on our perspectives and decision-making. These memos alongside our use of 2 coders and peer debriefing enhanced analysis trustworthiness.

RESULTS

DEMOGRAPHIC CHARACTERISTICS

Sixteen adolescents participated, with an average age of 15.2 years (SD = 1.5); half were identified as female (n = 8, 50%). Five of the adolescents (31.3%) had 2 to 4 medical appointments per year, 5 of them (31.3%) had 5 to 7 appointments per year, and 6 of them (37.5%) had 14 or more appointments per year. To protect the adolescents' confidentiality (some had rare health conditions), we did not ask about their health conditions.

POTENTIAL BENEFITS OF INVOLVING ADOLESCENTS IN THE EDUCATION OF MEDICAL STUDENTS AND RESIDENTS

IMPROVES PATIENT–PHYSICIAN INTERACTIONS

Participants discussed how they are transitioning from parent-accompanied to one-on-one physician interactions. They highlighted how they are often unsure how to communicate with physicians without their parents. They thought that their involvement in medical students' and residents' education could enhance their communication with physicians and improve their interactions with them: "Such involvement would teach me how to interact with the doctors, what to say, because I am not always going to be with my parents."

Participants commented on how they regarded medical students and residents as being in positions of power and that they were intimidated interacting with them:

> Sometimes I think a doctor is on a pedestal. He is like god almost . . . or a rock star and I know he can do amazing things. But I think it is hard for me to talk to him because he is better than me.

However, adolescents thought that being involved in medical education would facilitate their ability to be more open when talking to their doctors and would result in fewer awkward experiences, especially when they were by themselves at appointments.

Participants thought that their involvement could better prepare learners for the realities of interacting one-on-one with adolescents and facilitating dialog with them:

> Teens see things in a different way, in a way that doctors often don't. Teens can explain that perspective to doctors, which is good and then they [doctors] can improve how they talk and interact with us.

By providing learners with insights into what types of questions adolescents preferred to be asked and the tone in which they should be asked, adolescents thought that learners would be

> . . . prepared for the reality of actually working with us patients, cause for doctors they might have some better insight on what they are doing right and like what they are probably doing wrong just from listening to my stories and experiences of interacting with other doctors.

INCREASES PATIENTS' CONFIDENCE AND SELF-WORTH

Participants thought that their involvement in the education of medical students and residents would allow them to build on their existing skills, learn new abilities, and feel more confident:

> I am someone who really likes to help others. I am good at it, but I think this teaching would help me learn to cope better with my feelings. Teaching others about how I feel would be reassuring to me that I am okay and not by myself.

Participants discussed how educating learners might be viewed as challenging; however, they noted that rising to and succeeding in such a challenge would increase their confidence. They could set teaching goals, work toward them, and then experience a sense of accomplishment and increased confidence when they achieve these goals:

> You want to change the world . . . you have this big goal but what you need to do is create a bunch of small goals for teaching them [doctors] . . . so that you can actually do those small things and change the doctors' thinking or ideas about one or two things when they are with teenagers. . . . Then you will know you did a good job!

Participants also thought educating others about their health experiences would provide them with a sense of control and thus, increase their confidence:

> I would feel confident . . . I can direct where doctors should focus on improving with patients, especially on the mental side. I would feel I can actually make a big difference, especially in how they [doctors] communicate.

Likewise, another specified how providing the educational experiences would allow adolescents to "know their voice is being heard and they are making like an impact with things and in control, which is good."

Others also noted how educating learners would increase their sense of self-worth. They discussed how it would provide them with opportunities to witness how they can change learners' attitudes toward adolescents and thus enable them to feel that they have the power to make a difference:

There was a buddy program that I was in where they would match oncology patients with 3rd year medical students. . . . I know that one of the doctors actually chose oncology because she had such a good buddy experience and she bonded with that person, established a relationship with that person, saw cancer kids differently, and then it was so much so that she chose oncology. I think, you know then that you made an impact, that's pretty cool and makes you feel good.

Moreover, participants commented on how their educative roles could show adolescents that their "actions have a direct impact on doctors" and that they "actually did something that could cause something good for doctors and their other patients."

Encourages Patients to Self-Reflect and Gain Knowledge about Their Health Conditions and Themselves

Participants discussed how their involvement could be a beneficial intervention in itself for them too. They described how their educative roles would require self-reflection on their health experiences, conditions, and coping strategies. They noted how self-reflection could help them cope with their own experiences and feelings: "It allows us to cope with emotions." Participants thought that this self-reflection, combined with discussions that they would have with learners, would encourage them to learn more about themselves, their conditions, and how it impacts them: "It would make the teenager feel more comfortable about themselves or also educate themselves on their condition." Similarly, another said, "It makes me feel good, you know, about myself and really forces me to really pay attention to what I am doing to keep my condition good, and understand it to explain it to others."

Enables Patients to Socialize with Other Patients

Participants thought that allowing adolescents to be involved in medical education would encourage adolescent-to-adolescent networking, foster friendships, and develop a sense of community among participating adolescents. They commented on how the collaborative development of materials for learners would allow them to share their feelings and experiences with other adolescents and talk to others with chronic health conditions:
"In regards to creating presentations with other adolescents for residents, it gets kids to talk to some new kids too, especially if they are cooped up in a hospital, and it would be good to socialization with some other kids."

Another observed that, "Group projects to develop stuff for the doctors would be a good thing to do if you are stuck in the hospital, you could work with others and just talk to others about your sickness." Adolescents thought that these initiatives would be a way for them to make friends: "I get to meet up and talk about things we want to fix or topics we want to teach, it's kinda like a good way to make friends while doing it."

Potential Challenges of Involving Adolescents in the Education of Medical Students and Residents

Including Diverse Patient Perspectives

Participants acknowledged that some adolescents might not want to be involved. They commented on how the "pressure to perform" may be too much for some, especially those who are shy. They recognized that some adolescents are "super open and vocal" but that those who are "super quiet" could potentially be neglected in the development and delivery of adolescent-led educational initiatives. They acknowledged that those "going through difficult times" may not want "to share personal information because they are shy, don't like talking about things, especially a lot of emotional things." Participants emphasized that it is important for medical educators to recognize that not everyone is comfortable talking about themselves: "Not everyone wants to show their face." An adolescent's willingness to become involved may depend on "where their head is at." Thus "it's the person's own decision if they want to talk about it and be involved."

Managing Adolescents' Negativity

Participants commented that some adolescents might be angry or hostile with their health conditions: "I know I am not the happiest teen and it might be hard for the doctors to deal with me if I was teaching them." They thought that some adolescents might not be engaged or willing to collaborate in the education of learners: "If you get teens who aren't fans of doctors or the whole hospital thing, there is going to be a lot of negativity and bad feedback and bad teaching" or "The teens may not participate properly in the [educational] sessions or just leave the room." Adolescents also suggested that their "occasional self-centeredness" might impact their ability to teach learners.

Ensuring that Learners Are Nonjudgmental Toward Adolescents and Take Them Seriously

Participants worried that some learners would not take them seriously or listen to them: "Will doctors actually take it to heart?" They wondered if learners would dismiss what adolescents are teaching or view adolescents' stories as teenage angst or overreactions irrelevant to clinical practices. One expressed concern about "maybe being pushed aside" and worried that the doctors "will think I am stupid." Participants also questioned how honest they could be in teaching about coping strategies or about what they value in physician interactions:

I know I would be a little self-conscious about explaining how I cope. I know I shouldn't smoke but I do and they would probably be critical of me.

They discussed how learners might take offense at adolescents' use of personal examples when addressing undesirable physician interactions. Participants worried whether learners would "take it in a bad way" or think that it was "demeaning to them and they would not like it."

DISCUSSION

This study builds on the potential benefits and challenges included in the adult patient conceptual framework developed by Lauckner et al.[3] With regard to benefits, participants thought that their involvement would improve patient−physician interactions, increase adolescents' confidence and self-worth, encourage adolescents to self-reflect and gain knowledge about their health conditions and themselves, and enable them to socialize with other patients. These findings fall within the broad potential benefit categories suggested by Lauckner et al[3] of "personal learning" and "making valued contributions." Nonetheless, this study provides more specific categories that describe potential benefits of patient involvement from adolescents' viewpoints. These benefits also align with those reported by adult patients in other studies. Researchers have shown that adult patient involvement improves bedside manner and history taking,[5] patients' understandings of physicians,[1] and reduces power imbalances between physicians and patients.[15] Additionally, they have found that adult patient involvement positively contributes to patients' self-esteem and empowerment[6] and reduces patient loneliness.[5] Moreover, research has shown that such involvement provides adult patients with opportunities to self-reflect on their medical histories and health experiences, as well as gain new or deeper insight into their lives, coping strategies, and conditions, especially the emotional aspects.[5]

The study findings also advance existing literature by highlighting benefits that are unique to adolescent patient involvement in medical education. As mentioned, adolescent patients are becoming less reliant on their parents and more independent, including in their physician interactions. Moreover, adolescents value socializing and developing friendships while in the hospital. Their involvement in medical education can allow them to feel more comfortable with physicians and provide them with opportunities to collaborate with other adolescents. Such opportunities can enhance adolescents' emotional intelligence, particularly their self-awareness, empathy, and social skills, and influence self-identity development.[16]

Despite these benefits, participants discussed potential challenges with regard to their involvement. These included sharing diverse patient perspectives, managing potential adolescent negativity, and ensuring that learners maintained a nonjudgmental attitude toward the adolescents. Within these findings, participants alluded to ideas presented in the conceptual framework by Lauckner et al[3] categorized under the general challenge of "potential vulnerability." However, the adolescents provided details that enabled the formation of additional and more precise categories for the potential challenges of adolescent patient involvement in the education of medical students and residents. Other existing literature on adult patient involvement in medical education also illuminates a few of the potential challenges that the adolescents suggested. Researchers have emphasized the importance and difficulties of involving diverse groups of patients in educational initiatives.[17] They have also highlighted adult patients' concerns about learners judging them[6] or healthcare professionals undervaluing and dismissing their perspectives.[3]

Unquestionably, patients of all ages may find their involvement in medical education daunting, because the information that they share is personal and emotion-ridden.[18] However, the emotional turbulence of adolescence may intensify these feelings and thus impact adolescents' willingness or ability to contribute to medical education. In this regard, our study underscores the distinctive challenges faced by those designing and implementing educational initiatives with adolescents. However, we believe that adolescents' passion (whether it is negative or positive) about their health conditions or experiences is something that is important to harness and share with medical students and residents, because it can foster positive changes in learners' practices, which in turn benefits adolescent patients.

LIMITATIONS

We only included English-speaking adolescents with chronic health conditions from 1 center; thus the findings are not transferable to all adolescents. It is also possible that those who participated were more interested in medical education than those who did not participate. We did not explicitly ask the participants if they had previous involvement in medical education, nor did we require such previous involvement as a study eligibility criterion. Additionally, we did not differentiate between those recently diagnosed and those who have had their health conditions for years. Moreover, we did not distinguish the findings based on participants' ages. Such limitations can be mitigated with future multisite research that asks participants about their previous involvement in medical education and includes outpatients, as well as those who are in different stages of their chronic health conditions or adolescence. Next, we acknowledge that our perspectives informed our data interpretations, and individuals with different perspectives may glean other interpretations. We also did not have participants validate our data interpretations. Therefore future participatory research where adolescent coresearchers are involved in data analysis is needed.[19] Finally, we coded data inductively to provide a description of adolescents' perspectives; however, we advocate for additional studies that move beyond description to theory generation.

CONCLUSION

Healthcare professionals are involved in learners' education, but adolescent patients are often excluded or only included in passive roles (eg, as clinical "material").[5,20,21] This study highlights the potential benefits and challenges of adolescent involvement in medical education. We are hopeful that it will encourage medical educators to consider these benefits and challenges in designing and implementing innovative educational initiatives that involve adolescents. The identified benefits may also

provide medical educators with justifications for partnering with adolescents in educational initiatives and provide them with insight into what adolescent patients value in involvement. Throughout the design and implementation of these initiatives, it will be important to explore further the benefits and challenges of adolescent involvement. As demonstrated by this study, adolescents, when provided with opportunities to share their perspectives, are valuable contributors to our understanding of topics.

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